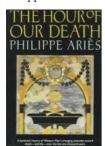
# reviews

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#### The Hour of Our Death

Philippe Ariès



Oxford University Press 1991 (Alfred A Knopf 1981), pp 651 ISBN 0 19 507364 9 This classic book is currently out of print, but may be available from libraries and online secondhand bookshops

Rating: ★★★★

hilippe Ariès was one of the most highly regarded social historians of the second half of the 20th century. His first essays on the history of death appeared in 1975, just when emerging medical capacities to keep people alive on ventilators to the end of the tax year had given a whole new meaning to the biblical adage to render unto Caesar what is Caesar's and to God what is God's. Aware of changing attitudes to death, and wondering if we were facing a radical break with a continuous tradition embodied in the rituals of visiting cemeteries and in piety for the dead, Ariès continued his work on this subject, which culminated in 1981 in this book, a work of exciting scholarship and humanity. Exciting because, using the history of large urban cemeteries, ancient funerary practices, notarial records, wills, and works of literature and art, Ariès shows that far from there being a continuous tradition regarding death, our current "alienated" forms of death have replaced a relatively short lived tradition of romantic death that started with the Victorians

In contrast, from the early Christian centuries through to the Middle Ages the promise of eternity seems to have shaped considerations of death, leading our ancestors to more or less abandon corpses to the Church. In the Middle Ages a change of culture brought a growing concern with the fear of judgment, which eventually trumped the promise of eternity. The focus on death changed from a communal one to a much more personal one. Previously a good death was one that came on slowly, was anticipated by the sufferer, and took place in the presence of others. A bad death was one that came abruptly, leaving people unable to settle their mental or worldly affairs.

The rise of modern individualism has seen a growing preference for abrupt deaths. The bodily indicators of death that once allowed people to compose themselves and arrange their affairs have been transformed into signs of bodily corruption. A fascination with bodily changes before and after death ultimately issued in a new mythology: the perverse resurrection of vampirism. These changes also set the stage

for the increasing role of medicine as a means to stave off the corruption of death. With Tolstoy's *Death of Ivan Ilyich* we see how the interventions of doctors led to a move from resignation in the face of death to anxiety as to whether the efforts of doctors will succeed in prolonging life.

While Ariès illustrates how each of us might have faced death at various points during the last 1500 years, his ultimate interest is in how communities face death. The relatively rapid transformations in our understanding of death reflect our capacity to make myths and to embody these myths in communal and personal memories. This myth making capacity seems even more active-and perhaps is ever more needed-in our modern scientific era. Any juxtaposition of myth and science is unsettling, but this tension finds a resolution within the bigger picture that this book gives, and thus the book is not just a profound work of historical scholarship but also one to consider giving to a friend who has been bereaved. The Hour of Our Death might even appropriately be called a book of consolation, if that word could be stripped of the connotations of piety that have encrusted it in the last 100 years and that have left us unsettled by the changing face of death in our time.

**David Healy** director, North Wales Department of Psychological Medicine, Bangor Healy\_Hergest@compuserve.com

# And When Did You Last See Your Father?

Blake Morrison



Granta, £7.99, pp 224 ISBN 1 86207 093 8

Rating: ★★★★

ooner or later we all die. And so do our parents. Blake Morrison has generously offered his insight into the experience of losing his father. This book met with critical acclaim on its publication almost 10 years ago and has inspired similar confessional memoirs. It is a

testament to the quality of Morrison's writing that details of everyday family life and death, not sensational trauma or dysfunction, are what engage the reader. Between vivid descriptions of his father's death from cancer he recounts quirky, sometimes painfully funny anecdotes. His father's self centred impatience and interfering ways are tempered by true love and affection. It is this focus on ordinary details, such as a fondness for cars, practical jokes, and a series of dachshunds named Nikki, that give this book a wide appeal.

Of course, there is no escaping the sad conclusion of this story. Dr Arthur Morrison had a good death, at home and surrounded by family. Perhaps because the author grew up with doctors as parents he has the ability to provide compassionate and rich details of scenes in hospital and at the deathbed. These unsentimental passages of a death at home are some of the most compelling in the book.

Modern life has a way of detaching us from the uncomfortable images, mixed emotions, and strange conversations of the final stage of life. Morrison writes, "I used to think the world divided between those who have children and those who don't; now I think it divides between those who've lost a parent and those whose parents are still alive."

He cautions the reader against underestimating the strength of the grief of sons and daughters, no matter what relationships between parents and children are like. As much as I hate to, I have begun to contemplate this advice when it comes to my own mother, who in October 1998 was diagnosed as having heart failure, diabetes, and other health problems. I am grateful for this warm, nostalgic, but unsentimental book.

**Tamara Rader** *BMJ Knowledge* trader@bmj.com

Items reviewed are rated on a 4 star scale (4=excellent)



### Death becomes us

ccording to www.deathclock.com I will die on Tuesday 14 March 2051. At the time of writing that translates to 1504 875 429 seconds left of living. But when my time comes will I die the death I want?

Perhaps the best way to die is to do so in a way that leaves the possibility of living again. Arrangements can be made at the Alcor Life Preservation Foundation (www. alcor.org) to cryopreserve your body—that is, to freeze it in liquid nitrogen for future resurrection. Once medical technology catches up, proponents of cryonics claim, it may be possible to have your suspended body revived, the cause of your death cured, and your aged and damaged cells repaired. Cryonics is touted as an extended form of artificial resuscitation: you wouldn't deny a paramedic resuscitating your heart after it stops beating, would you?

For those curious about death and the funeral industry, www.msprozac.zoovy.com (which is run by a webmaster battling advanced stage breast cancer) gives information on the dying process and how to plan for death. Death, after all, is a part of life, the site says, but this is mostly a commercial endeavour, and its embalming details and autopsy memorabilia may leave some people feeling queasy.

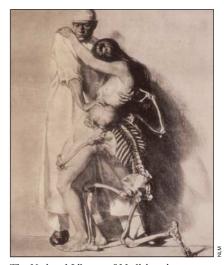
Advice on living wills (also known as advance directives) has proliferated on the web, much of it linked to the thriving funeral and insurance industries. From a healthcare perspective, the American Medical Association's online booklet (www.ama-assn.org/public/booklets/livgwill.htm) provides use-

ful instruction to people wanting to document in advance their dying wishes and to designate an agent to execute treatment decisions if necessary. You can register your living will in the United States at www. uslivingwillregistry.com and in Canada at www.sentex.net/~lwr/index.html

The international site www.partingwishes. com has clever page wizards to help you securely document your preferences for burial or cremation, write a will, and design a future web based memorial. Online advice on creating your own funeral is hard to come by, but at www.allen-nichols.com/products.cfm you can buy a popular workbook. Any memorial service is unlikely to come cheap for your family (http://observer.guardian. co.uk/Print/0,3858,4681030,00.html). the bereaved who are planning funerals and juggling the various financial, legal, and practical decisions that accompany the death of a loved one, the Vancouver based www. funeralswithlove.com is a gentle, compassionate resource.

The death websites at www.selfgrowth. com/archive/death-websites.html from the bizarre to the sublime. Of these, death-dying.com offers perhaps the broadest range of content on death, dying, bereavement, and caregiving, mostly geared towards non-professionals. Unlike other sites, it includes sections on dealing with sudden deaths such as suicide and murder. Self assessment tools, chat rooms, book reviews, question and answer forums with experts, and a personalised email service of grief support are offered, and its content appears to be updated regularly. A series of provocative personal views—some touching, others ranting-might provide comfort to those experiencing the rollercoaster of grief.

A good death is emphasised at Growth House (www.growthhouse.org), an educational site for healthcare professionals and consumers on life threatening illness and care at the end of life. Special sections on the death of infants and children and on pregnancy loss have comprehensive advice



The National Library of Medicine site (www.nlm.nih.gov/hmd/hmd.html) has an outstanding history of medicine collection including *Physician Struggling with Death For Life.* Photogravure by Ivo Saliger

that will probably help people. But its professional content is thin. The section on quality improvement, for example, lists a series of organisations rather than examples of best practices or clinical guidance. Perhaps its best feature is its hosting of the inter-institutional collaborating network on end of life care, an online international group of palliative care organisations.

Palliative Care Matters (www.pallmed. net), founded by a consultant in Wales, provides news, scientific articles, drug advisories, job postings, conference announcements, and regular updates on governmental happenings for healthcare professionals working in palliative care in the United Kingdom. Forums are also hosted. The site is detailed and user friendly, with a "quick update" link that lists content posted within the previous seven days.

Celebrating the dearly departed, www. mexconnect.com/mex\_/feature/daydead index.html provides a fascinating, if frenetic, series of photo and journalistic accounts of Mexico's Día de los Muertos, or Day of the Dead. The festivities involve such customs as macabre adornments and lively reunions at family burial plots, chocolate skulls and skeletons, fireworks, and seasonal flowers such as cempazuchiles (marigolds) and barro de obispo (cockscomb) that serve as offerings to the dead. www.darwinawards.com slyly commemorates individuals who eliminate themselves "in an extraordinarily idiotic way" from the gene pool.

If you wish to seek solace in the words expressed in the moments before death, choose from the last words of famous people (www.geocities.com/Athens/Acropolis/6537/index.htm) or the rather sprightly Japanese *jisei* (death poems) at www.samurai-archives.com/deathq.html



Detail from a Day of the Dead costume, Mexico

**Jocalyn Clark** *editorial registrar*, *BMJ* jclark@bmj.com



# It's never been a better time to die

A look at the changing art of obituary writing

or people hoping for posthumous recognition, there has never been a better time to die.

For a start it's summertime, the season when obituary copy traditionally runs dry. More importantly, obituaries are enjoying the type of popularity once reserved for England's cricketers, the London broadsheets are devoting more space to recognising the recently departed, and there is even an International Association of Obituarists, which holds an annual conference to explore developments in the field.

You may think this is taking the business of dying a bit too seriously. But the world, it seems, is full of secret obituary readers who are gradually coming out of their closets. Mention at any dinner party that you are an obituary writer and someone always admits to turning to the obituary page first. And they are, er, dying for more.

It's not just the dry bones (excuse the pun) of a life lived that these enthusiasts want to read. They want some flesh to chew on. A little bit of gossip goes a long way; a light sprinkling of scepticism over what

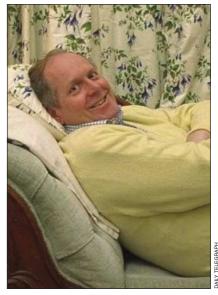
otherwise appears to be a blameless life makes for an interesting read.

Newspapers and journals have long carried factual notices of death, whether as paid-for death notices or simply as reports of the event as a piece of news. But a good obituary demands something more. Sometimes the manner or cause of death can itself be newsworthy. That of Dr Phil Williams, the former Plaid Cymru member of the Welsh Assembly who died in June in a seedy massage parlour called A Touch of Class, is a good example of an unexpected—and therefore reportable—way to go.

We have to look back to the mid-1980s to date the arrival of the obituary as an art form. It was started, depending on your allegiance, either by the arrival of a new obituaries editor, Hugh Massingberd, at the *Daily Telegraph*, or the launch of the centre left broadsheet the *Independent*. Whichever it was, the obituary as an entertaining piece of writing was soon being developed by the other major national newspapers. Thereafter the idea of the obituary as a feature that went beyond a notification of death and list of achievements spread to specialist publications (such as the *BMI*) and across the Atlantic.

The International Association of Obituarists was founded some six years ago by a former teacher, Carolyn Gilbert, a Texan with a fascination for reading about the lives of people she had never met. "We are a virtual centre for the art of the obituary," she says, talking about how ideas, articles, and information are posted on the association's website. "But I would like it to become an academic institute."

Once a year she brings together obituary writers, editors, and aficionados



The innovative Hugh Massingberd

from across the world. On this year's agenda were discussions about good deaths, how to approach grieving relatives, and dealing with complaints.

Also under the spotlight was that trickiest of subjects, how to decide who makes the page. Boiled down, the answer was "editorial judgment"—the same as for every other page of a newspaper, magazine, or journal. Is the subject interesting? Does the author give it entertaining treatment?

Among those who spoke was Steve Miller, the newly appointed obituaries editor of the *New York Sun*. He was working for a Wall Street investment firm while publishing an occasional, highly irreverent magazine of obituaries, *Good Bye!* Then came the attack on New York on 11 September 2001. Miller was in the second tower of the World Trade Center. He escaped the destruction, but his job vanished in the debris.

He illustrated the difficulty the obituarist can face in creating an accurate but interesting summary of a life by comparing the task to the difficulty he has recalling the events of that terrible day: "If a few minutes of my own life—moments of irredeemable clarity that spanned at most a couple of hours—are so difficult to get right," he says, "how much harder is it to present a truly accurate version of an entire life in 20 or 30 newspaper inches?"

Speaking to colleagues, family, supporters, and detractors helps obituary writers build a picture. The author can then, if appropriate, say on the one hand that the deceased was a successful inventor and on the other that he or she was a manipulative little shit. It is not always necessary for the author to reach a judgment. Others will no doubt do that. What is important is that the author gives the reader an entertaining read. And with so much more interest nowadays in the obituaries pages, standards are undoubtedly rising.



Custer National Cemetery, Big Horn County, Montana

**Tim Bullamore** freelance obituary writer tbullamore@aol.com

### A death photographed: one patient's story

Michael Willson managed his death in his own way. Having photographs taken was an important part of this management, and the images were pinned up on the walls all around him in his house. More photographs are shown on bmj.com, and below are Michael's own words on the project, as well as comments from his general practitioner and the photographer

ichael Willson, who was born in 1947, was a self employed psychologist who did consultancy work for the probation service. He was very well respected locally and nationally. He was a free spirit and charismatic and had a wide circle of friends. He liked riding his horse bareback.

In 1994 he presented with anaemia, epigastric pain, and malaise. Gastroscopy showed carcinoma of the gastroesophageal junction. He underwent oesophago-gastrectomy with splenectomy, but unfortunately tumour was present at the resection margins. He declined the offer of palliative chemotherapy. At this time his prognosis was poor. He had very mixed emotions about his prognosis, including surprise that he lived longer than expected.

He wrote a paper called "Post-gastrectomy gastronomy," which was published in a medical journal. Once he realised he was not going to die imminently he travelled and took on some work. He was determined to die at home rather than hospital, and when he became more ill he asked for regular contact with friends. His friends organised a rota to care for him 24 hours a day. The carers included his wife and two senior doctors who were close friends. He died peacefully at home in 1996.

#### The patient

As you steam past 40 you start to ask yourself "Who have I become?" rather than "What am I going to be?" until, in the last days of your dying, you find an answer. If you have time, you can also use the last months to compose the last movement of your sonata in which the previous themes are not just repeated but are combined into a further final theme. But this is an activity that requires attention, which in turn requires objects, thoughts, and images to carry it.





Sitting for and then studying these photographs has been very valuable in this respect. The photographs provide many different images and perspectives, whereas staring into the mirror provides only one. And the photographs provide me with sequences of images, some linked by the three second gap between each exposure and others though their documenting how I change each week as my body leaves my mind.

The face, the place, the body, and the context become objects to be placed against each other and understood together and then, so it seems, to be separated again from myself.

These pictures are not for the album and later reminiscence; they are for now.

#### The photographer

Michael encouraged me to photograph his experience, to help us both. His attitude to dying provides an alternative to the traditional stereotypes. It is possible to die well. Photography helped Michael define his identity and to deal with his terminal illness. I believe that he derived benefit from a creative process that also challenges society's taboo concerning the depiction of mortality.

One sequence of portraits (see bmj.com) showed three expressions in as many seconds: posing for the camera, seeing his image reflected in the lens, and confronting the reality of dying. We agreed that the project should include pictures taken after his death. In his death announcement, which he wrote himself, Michael asked mourners to contribute by allowing the work to continue. He gave written consent for the posthumous use of the images.

#### The doctor

It was very challenging managing this highly intelligent man. Symptom control enabled him to live the way he wanted. I cannot remember a patient with whom I shared more philosophical debates and jokes in the last few months of life. He was very proud of the coffin he had built himself and took great pleasure in showing our specialist nurse how well he fitted in it.

He was particularly proud of the photograph of him wearing the bowler hat and the expensive handmade suit that he used for his court appearances as an expert witness. His funeral took place in the field near Sheffield where he used to ride. The funeral service was determined by Michael. Friends and family were invited to "wear a hat and be prepared to sing lustily." We celebrated his life by singing "All You Need is Love" by the Beatles. Palliative care helped him to die entirely on his own terms. I felt honoured to be involved in his care.

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**Paul Schatzberger** *general practitioner and photographer, Sheffield* 

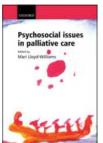
**Sheila Payne** professor of palliative care, Trent Palliative Care Centre, University of Sheffield

This article has been produced with the full consent of all concerned.



P+ More photographs are shown on bmj.com

#### Psychosocial Issues in Palliative Care



Mari Lloyd-Williams (ed)

Oxford University Press, £24.95, pp 208 ISBN 0 19 851540 5

Rating: ★★★★

The title of Lloyd-Williams' book makes for an interesting reflection. Palliative care was born with the hospice movement as a response to a medical service that seemed unable or unwilling to care adequately for dying people and their families, so the concept of psychosocial issues should be embedded in it. However, increasing subspecialisation and advances in medical technology mean that those original values are at risk of disappearing. It is therefore encouraging to see that such a dynamic specialty is able to observe itself critically and tries to avoid further departure from the definition the World Health Organization gave of palliative care in 1990: "Control of pain, of other symptoms and of psychological, social and spiritual problems.

Advocates of the biomedical model could claim psychosocial issues to be out of place in an evidence based culture, but all of the contributors make excellent reviews of the literature that prove otherwise. The chapters are full of sharp references and are empty of wasteful philosophical interpretations or of personal opinions. This reinforces greatly the need for psychosocial issues to be taken more seriously in the development of services, as the actual provision seems to fall very short of what would be acceptable, let alone ideal. After the foreword and the preface the book defines its title, and this first chapter sets out very well the scope of the following chapters. The book covers many different aspects, from communication skills to service provision, anxiety and depression, spiritual care, non-malignant disease, bereavement care, and carers and staff, and the final chapter looks at the future of psychosocial care. However, I missed a chapter looking at ethical issues in palliative care, from research to patient autonomy and euthanasia (even when the last topic falls outside the philosophy of palliative care).

The book concludes by highlighting the need for good quality research in psychological, social, and spiritual areas of palliative care as a priority for the future.

This is an excellent book, to be celebrated not only because of the area it covers but also for the high quality of its contents.

**Ignasi Agell** specialist registrar in liaison psychiatry, Leeds General Infirmary iggy@agell.freeserve.co.uk

#### PERSONAL VIEWS

# The good of small things

first met "Salmah" when she was about nine. She had cerebral palsy and had spent her life confined to her bed or wheelchair, relying on her family for her every need. To some people it might seem a useless or meaningless existence-always needing someone there to turn, change, or feed her. Yet these were acts of love that her family carried out devotedly. Most of the time she would show no sign that she saw or heard much. Quite often what I elicited were grimaces or protesting moans as I tried to move her stiff limbs while examining her. Once in a while she would surprise us with a broad grin or a near chuckle, as if sharing a good joke.

As time went on I felt increasingly inadequate, with little to offer except regular prescriptions of anticonvulsants or suggestions to improve her seating or her constipation. She grew larger, making it more difficult for her family to move her. Transportation

became a complicated logistical exercise.

One of her last admissions to hospital was a prolonged one. What started out as a simple case of pneumonia developed into a severe illness. The subject of possible options in the event of her deterioration was raised. We explored her family's opinions on ventilation and intensive care. I encouraged her parents to discuss the matter with her young adult siblings who were closely involved with her care. Their answers were non-committal, and they left it to me to decide "whatever was best." It was difficult to gauge whether this was a reflection of their trust or whether they wanted me to ease their burden of responsibility for a decision to let her go. I hoped that I would not have to confront that decision but feared that she would never see her home again.

Then, miraculously, with a few adjustments to her nursing care she managed to recover sufficiently to be sent home. Her parents left with a list of emergency telephone numbers and a promise from me to drop by one day.

I fell prey to the sin of procrastination, as other matters cried for attention—although I kept reminding myself to visit her soon. A month later her parents sent me a message to say that she had passed away the previous day and that they were grateful for our help.

Stricken with guilt that I had not fulfilled my earlier promise, I paid her family a visit later that day. She had been buried the previous day, according to custom. Her family was in the midst of preparations for memorial prayers that evening when I dropped in. Her parents were surprised at my visit yet greeted me warmly and apologised for the

bare living room, from which all the furniture had been cleared.

We sat down together on the floor, and they pressed me to have some tea as we spoke of many things. They related the events leading to her death. She had been relatively well and happy after her return home. They had celebrated her birthday only the week before. Then she had developed a slight fever. It seemed like a mild illness and did not cause any alarm, but she had passed away in her sleep that night. She had died in the arms of her sister, who usually slept with her.

They told me about her funeral and how relieved they were that everything had gone

Everything we do

for our patients

beyond what we

has a value

perceive

smoothly and that the proper rites had been observed. We exchanged knowledge about various customs of our respective cultures in relation to death and mourning. Salmah's family belonged to the local Malay Muslim community, while my roots were Indian

and Christian, yet our different worlds had some basic similarities.

Her family showed me pictures of Salmah from the family album. There were photographs of her as a baby and at different stages of growing up. It was an enlightening experience to look at her through a different prism—not as a patient whom we might classify as "completely dependent" but as a beloved member of her family, in everyday situations and pretty clothes, and included in family events and celebrations. They proudly introduced me as "Salmah's doctor" to members of her extended family.

I had ventured on this visit with some trepidation, uncertain of the reception I would get. The warm hospitality and the opportunity to speak with her family opened my eyes to things I would never have known otherwise. Had I not made that trip I would not have appreciated how much she meant to her family. I learnt that many little actions over the years, which I may have considered insignificant or even pointless, had a great impact on easing the situation for Salmah and her family. They knew and accepted that this end was inevitable. What mattered to them was that she had managed to return home and had departed peacefully in familiar surroundings with her loved ones close by. This was much needed reassurance for me that everything we do for our patients has a value beyond what we perceive. To Salmah, who taught me these important lessons, may your soul rest in peace.

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# Freedom from pain goes a long way to a "good death"

There was no real

sedation and side

analgesia, only

y sister in law died of metastatic malignant melanoma five years ago, leaving behind a six year old boy, a four year old boy, and a pair of 10 month old twins. My recollection of her last weeks is pain, pain, and more pain.

A year after her death the family attended a bereavement weekend at Winston's Wish—a charity that supports bereaved children and young adults—in Gloucestershire. Winston's Wish offers young people support and information to help them understand what has happened, slowly allowing them to learn to live with their loss. The charity has worked with over 2000 young people since 1992.

The charity workers' greatest skill is in

encouraging children to communicate non-verbally. On their weekend the children were asked to colour sand and pour it into a test tube. Each colour had a particular meaning. The

children were asked to write on a piece of paper what the colour meant to them, with reference to the person who had died. They were also asked to write on a porcelain plate anything that had made them angry about their loss. They then threw the plate in the bin, listening to it as it shattered. My four year old nephew coloured his sand red. He explained that the red was for "PAIN." My eldest nephew wrote PAIN on his plate and shattered it. In the discussions that followed both boys were able to articulate their memories of the screaming that came out of their mother's room as she was dying. My brother corroborated their memories: he recalled that every time she screamed she



A child at Winston's Wish: I light my candle on important days when I want to think about my dad

was given more diamorphine. After each dose of diamorphine she either slept or became paranoid.

There was no real analgesia, only sedation and side effects. Why? It is a question that has plagued me ever since. Here she was being cared for by a good palliative care service in London, experts in WHO's "analgesic ladder." Yet, if you now ask any member of the family whether she had a good, pain free death, the answer will be a categorical "no." Pain is multifactorial. It is impossible for relatives of patients—even when doctors—to objectively assess their pain. I was a newly qualified consultant in palliative care at the time, and my memory of complete impotence remains. Over the years since my sister

in law's death I have come to realise that her experience is not the norm. I have, however, seen other people whose pain has been equally difficult to control.

Looking back, I wonder whether some patients just did not respond to morphine. This has been shown to be the case for codeine: 6-7% of white people do not respond to this drug. Genetic variation can be a powerful factor in pain relief. It is reported that between 10% and 30% of patients treated with oral morphine have either intolerable adverse effects or are inadequately treated, or both. The reason for this variability has not yet been shown.

Today, many more analgesic drugs are available. Opioid switching—changing from morphine to an alternative opioid—is gaining popularity in pain management. Its aim is to improve a patient's response to analgesics and to reduce adverse side effects.

At present most patients have a pain free death. A significant minority, however, do not. It is for such patients that research is needed. The goal would be to identify patients who do not respond to morphine, before analgesia is given, and then to find an effective alternative analgesic.

Research has begun. My hope is that in the future a good, pain free death can be the right of everyone, so that other people do not have to go through the extreme distress suffered by my late sister in law, my brother, and their boys.

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We welcome submissions for the personal view section. These should be no more than 850 words and should be sent electronically via our website. For information on how to submit a personal view online, see http://bmj.com/cgi/content/full/325/7360/DC1/1

#### The Art of Dying

A year long programme of events at King's College, London ended this month www.kcl.ac.uk/depsta/humanities/art\_of\_dying

o understand what constitutes a good death we need to think beyond medicine and explore insights from the arts and social sciences. This month has seen the end of The Art of Dying, a year long programme at King's College, London, that brought together clinicians, social researchers, philosophers, historians, lawyers, theologians, and ethicists.

Hosted by the college's Department of Humanities, The Art of Dying comprised debates, lectures, conferences, exhibitions, and performances that provided a forum for leading scholars to discuss the concept of a good death and how it has changed over time and across cultures. Members of the general public, medical students, and a range of healthcare professionals were also involved, together with artists, actors, writers, musicians, classicists, linguists, and designers. Events between October 2002 and July 2003 included a season of films on dying, an exhibition by Helen Story, called Death Dresses, which used textiles to tell a non-morbid story of death, and many discussions exploring the depiction of death in music, philosophy, art, and literature. One of the best attended events was a performance of Nell Dunn's play Cancer Tales (BMJ 2003;326:1151).

Nicholas Christakis, professor of medical sociology at Harvard Medical School, was one of the guest speakers. He said, "The issue of a good death is a neglected and fundamental topic. Who could argue against a good death?" Dr Christakis was particularly struck by the interdisciplinary nature of the symposium, which he says benefits doctors as they "are invited to be sceptical and self critical of their own ideology and perspective." He said, "Both the variety and consistency across time and space about the idea of a good death can and should be instructive for doctors as they think about death in medicine and their own death.'

According to Professor Irene Higginson, one of the organisers of The Art of Dying, the symposium helped to "deepen the debate about dying," which she says was reflected in the changing nature of the discussions over the year. Professor Higginson said that the major impact of the symposium had been "to make people realise that there are many individual facets of a good death and that we should not be frightened to talk about it."

**Upasana Tayal** Clegg scholar, BMJ tayal@bmj.com

#### PERSONAL VIEWS

# A perfect death?

his is my experience of death. My husband, David, died in November 2002 in his home at the age of 66. I am 54. He died on his bed, alone. The day before he died was beautiful. We had walked along a steep part of Offa's dyke, near Knighton. He had no angina and was quite fit.

David died 10 or

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David had retired in 2000 from running a stressful architectural practice. I was doing locum work, which enabled us to travel widely. He walked the dog each day and was turning into an expert in vegetable growing. He did not smoke

and drank a little. His family was small, and his father had died from a stroke at the age of 69.

That day I had gone to work in Telford, doing a surgery from 10 am to 12 pm and from 2 pm to 4 pm. During the lunch break I tried to phone him, as I always did. There was no reply, and during the afternoon surgery I became more anxious as there was

still no reply. I finished promptly and drove straight back. It was getting dark, and my anxiety increased when I saw that no lights were on in the house. The door was shut but not locked. The dog was in her basket downstairs. I climbed the stairs, and there he was asleep on the bed—no, not asleep, dead. He was smiling and looked quite peaceful. No

struggle. No vomit. No sweat.

A year earlier he had an episode of rectal bleeding and had had a colonoscopy under general anaesthetic. A few benign polyps were found. He was not hypertensive or overweight. A

year before that he had had an upper gastrointestinal endoscopy, as he had persistent heartburn. The endoscopy showed Barrett's oesophagus. Since then he had taken daily lansoprazole, but not aspirin.

The postmortem examination showed "moderate triple vessel atheroma (70% narrowing). Left anterior descending coronary

artery occluded by thrombus near to its origin. The thrombus is brown suggesting formation some time before death (ie at least a few hours). Moderate generalised atheroma." There was no evidence of Barrett's disease or large bowel polyps.

My son is also a doctor. We both ask ourselves if we missed something. Could we have done anything had we been there? Would David have been better in coronary care and spending the rest of his life as a cardiac cripple? In our opinion, David died 10 or 20 years too soon, but he died peacefully. He would not have wanted it any other way—in retrospect, nor do we.

Why have I written this? Maybe it is a purely selfish action to help me in my grieving process. I hope it is more than this. I want doctors to have less horror of death and to take much more care of people when they are dying and of their relatives.

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### Freddie

t 12 years old, he'd already been unwell for a long time: congestive cardiac failure secondary to cardiomyopathy; a rare cause of this condition in my limited clinical practice but common in the population he came from. He'd been receiving maximal therapy for months now, his dutiful carers ensuring he took his furosemide and enalapril every day, going so far as to grind them up into his meals when he—as happened increasingly often—refused to take them.

When they called me in to see him, I was shocked by just how bad he'd become. I'd known him his whole life, and in my mind he'd always remained as sprightly as the first time I saw him playing with his siblings. Things were different now. Even from the end of the bed, I could see that his breathing was laboured. When I got closer, I noticed how his eyes, once shiny with mischief, were dull and glazed.

At one point in my life he'd been my constant companion, and it broke my heart to see him in such a state. I'd seen his echocardiographic report six months before—poor left ventricular function and a vastly diminished ejection fraction—and had known that it would come to this, but it did not make things any easier.

My mother and I agreed there was only one thing to do. We took our beautiful black tom cat, Freddie, to the vet. The vet—a feline specialist who had performed the echocardiography and started him on the life prolonging drugs—was highly professional, her discussion with my mother a masterpiece in the art of breaking bad news. "What were the possible outcomes you were thinking of as you drove here?"

How many times have I sat at the other side of the table, hoping relatives will break their own bad news, trying to feign neutrality

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while gently conveying the message that there is nothing more to be done? At least this time there was actually a choice. Freddie wasn't going to get better, and she had the means to end his suffering in a humane and compassionate way.

We buried Freddie that night, buried him in our back garden on a bed of the

workshop sawdust he loved to play in, swaddled in his favourite jumper for sleeping on. We chose the spot carefully—beneath the apple tree where the afternoon sun streams across the house and hits the ground. A place he used to love to sit, a place he was at his happiest.

A couple of weeks later, we received a card from the vet. A simple measure of condolence, but the gesture moved us all immensely. I could not help but dwell on

the fact that, for all of the death certificates and cremation forms I have filled out, I have never once sent a card of condolence. I'd considered doing it on a couple of occasions, of course, but had somehow always concluded that it wasn't appropriate. Having now received such a card, however, I cannot think of anything more appropriate.

As I read, with increasing frequency, newspaper stories of terminally ill patients

having to make desperate journeys to Switzerland to avoid hopeless suffering, I cannot help but think of our beloved old tom cat, and how grateful we were that something could be done for him. I also come across more and more stories concerning general practitioners who have let it be known that they have helped terminally ill

patients go gently into that good night. These articles put me in mind of dear old Freddie, for no doubt these doctors are the same ones who have been sending cards for years; I, for one, feel I have much to learn from both them and our veterinary colleagues.

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# I dread not death but dying

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have long held the view that we must change our attitudes to prolonging life longer than is wished for or economically sensible, a view reinforced by an article in the *Independent* last November by Jane Feinmann describing how a leading cancer specialist with a tumour refused treatment that he routinely referred his patients for.

It is ridiculous that such a huge part of the NHS budget is spent on elderly people in their last year of life. I am 75. I chain smoke and drink a bit too much. I have atrial fibrillation, a much reduced vital capacity, and asthma. Forty years of spondylosis means that I have long needed anti-

inflammatory drugs and chiropractic treatment. Add touchy gut and irritable bowel syndrome and the result is that I take 14 different drugs at five different times each day.

Widowed 20 years ago, I have lived alone for the past 17. I have many interests and find little time when I don't know what to do with myself. I have always disliked the early morning, so I go to bed at 2 am or 3 am and get up at any time between 930 am and 11 am. I cook a wide range of the foods that I like, play music very loud (I am not deaf), and generally please myself. I manage alone, save for a gardener. But I have never found more than a small percentage of the human race interesting or bearable to spend time with. Most of my close friends have died during the past 15 years (including several doctors younger than myself), and none of my interests involve socialising, so I see other people socially only two or three times a week. I am perfectly happy with this.

Like any other thinking elderly person, I dread not death but dying. But it is not the likely pain and suffering that I most dread.



Thomas Braithwaite of Ambleside (d 1607) making his will, English School, 17th century

No, it is the probability that, unless I take relevant action, I will have to endure a possibly long period having to see unappealing (however well intentioned) people every day, and many times a day. I will have no choice of food, daily routine, or surroundings. This last aspect is probably the most serious, as I am like a prematurely exposed chick when I

am kept away from my shell (much of which I have designed or made myself).

Until a couple of years ago I had spent no time in hospital, apart from a minor operation in 1965. A few days in one local hospital and two pairs of days in another were, to me, far worse than anything Dante

could have dreamt up, and I am not just talking about squalor and inedible food. A year or so ago, when I experienced what I assumed was a terminal heart attack, I did not ring for help but sat down and wrote a farewell letter. Amusingly, after about four hours the pain's relocation made me realise that it must have been heartburn.

I was sickened a few years ago to see a television programme by Baroness Finlay about hospices. The state of what looked like live bait at an angling shop-which she insisted still had "quality of life"-made clear the extent of power that others can exert on the helpless and mindless. If Feinmann is correct, many doctors do not tell patients of their impending death and let them suffer invasive procedures, away from home and at huge expense. We should, when we feel the time is right, and perhaps with some hinting from our GP, be able to get an annual assessment of the probability of our being able to live the next year independently. (It might be necessary to explain "probability" to some people.) When the probability falls to a level that we personally-and hence without pressure-deem unacceptable, we should be able to be prescribed a drug to end our life comfortably and efficiently.

As things are, elderly people who wish to end their lives are put in the position of gambling on inadequate knowledge and means, which can result in more suffering and expense if their steps are unsuccessful. Only the knowledge that I have paid a fair amount in direct and indirect taxation assuages my guilt at my NHS drugs bill. Having been exposed to religion only through my observation of social phenomena (I am a psychologist by training), I resent my life being governed by the "spiritual" (a word I have never understood) beliefs of others.

**Brian Allt** psychologist and media research consultant, Sudbury, Suffolk

#### **SOUNDINGS**

# Environmentally friendly disposal of the dead

Funeral practices are succumbing to environmental concerns. Most bodies are either buried or burnt. With the proliferation of our species both methods have become problematic.

In ecological terms burial is environmentally friendly because it recycles the dead on an organic level, feeding worms and arthropods. But burial needs space and is therefore expensive. There is also the environmental risk of contaminating the water table.

Cremation dispenses with the problem of space, but the body is recycled as inorganic material. Hence cremation is wasteful and the process requires a great amount of fuel; moreover, the emissions contain noxious substances.

Although burial and burning are the most common ways of disposing of the dead, some cultures use other methods. Littoral cultures have often made use of burial at sea, offering the body to marine scavengers. Pastoralists living in semideserts cast bodies to hyenas and vultures.

Cannibalism deserves a mention, notwithstanding the fact that Jonathan Swift's advice to the Irish that they should eat their children is unlikely to find worldwide acceptance.

The most rational method of recycling would be to feed the dead to animals, which are good food converters and which, when their turn comes to be recycled, are nutritious and tasty.

In Christian countries, the eel and the pig seem to be suitable candidates. The Islamic world may have to settle for poultry. In Florida the prosthetic content of corpses would have to be considered. That state could take advantage of the tolerance of large reptilian scavengers for indigestible items, and alligator farming could be made into a pillar of Florida's economy.

Western man—unsentimental, rational, utilitarian—has overcome difficulties greater than those surrounding environmentally friendly and economic body disposal. Economists and environmentalists will solve the problems, and ways will be found to retain piety.

Piety must concentrate on the personality of the deceased and not on the corpse. Funerals unburdened by the presence of troublesome remains will take on new meaning.

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